DOCUMENT RESUME

ED 181 997 PS 010 751

AUTHOR Levenstein, Phyllis
TITLE Ethical Considerations in Home-Based Programs.
INSTITUTION Family Service Association of Nassau County, Inc., Mineola, N.Y.: State Univ. of New York, Stony Brook.
SPONS AGENCY Carnegie Corp. of New York, N.Y.: Children's Bureau (DHEW), Washington, D.C.: Education Commission of the States, Denver, Colo.
PUB DATE Apr 79
NOTE 16p.: Paper presented at the National Symposium on Home-Based Care for Children and Families (2nd, Iowa City, IA, April 24, 1979)

EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS Civil Liberties: Confidentiality: Early Childhood Education: *Ethics: Family Involvement: Helping Relationship: *Home Programs: *Home Visits: *Intervention: Parents: *Privacy: *Problems: Program Effectiveness: Social Workers
IDENTIFIERS *Verbal Interaction Project

ABSTRACT

This paper provides a checklist of 10 potential ethical problems associated with intervention in families through home-based programs. Problems which directly involve program participants are (1) pressure on parents to join the program, (2) violation of confidentiality, (3) intrusiveness, (4) need to respect the family's style of living, (5) giving assistance in matters beyond the home visitor's areas of expertise, and (6) giving more services than the home visitor can deliver and more than the participants want. The last four ethical considerations pertain to the ethics of program evaluation: the need for definitions of goals and method: for monitoring the quality of delivering the method: and for systematic program evaluation to provide evidence of program success. (Author/RH)

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ETHICAL CONSIDERATIONS IN HOME-BASED PROGRAMS[1]

Phyllis Levenstein

Verbal Interaction Project[2]
State University of New York at Stony Brook and Family Service Association of Nassau County, Inc.
5 Broadway, Freeport, New York 11520

PS010751

[1]Paper presented at the Second National Symposium on Home-Based Care for Children and Families, National Clearinghouse for Home-Based Services for Children and Families, University of Iowa, April 24, 1979.

[2]Supported between 1967 and 1979 for development and research of the Mother-Child Home Program by Marion R. Ascoli Fund; Carnegie Corporation of New York; Children's Bureau, U.S. Dept. of HEW; Education Commission of the States; Foundation for Child Development; General Mills Foundation; Grant Foundation; National Institute of Mental Health, U.S. Dept. of HEW; North Shore Unitarian Society-Veatch Program; Rockefeller Brothers Fund; and Surdna Foundation; and for research of the dissemination of the program by Rockefeller Brothers Fund and the U.S. Office of Education.

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ETHICAL CONSIDERATIONS IN HOME-BASED PROGRAMS

Phyllis Levenstein, Verbal Interaction Project of SUNY at Stony Brook and
Family Service Association of Nassau County, Inc.

INTRODUCTION

The first institution to conduct a home-based program for families was the family itself. Whether nuclear or extended, matrilineal or patrilineal, poor or rich, for most of mankind's existence families acted as mini-Departments of Health, Education, and Welfare. The family provided medical and nursing services, with an occasional assist from the local medicine man. Instead of schools, the family carried on whatever cognitive socialization of the young was considered necessary for survival, along with its more basic civilizing functions. And the family furnished as much social service to its members as it could afford from its own often meager resources.

Outside institutions gradually took over a large part of these family functions. People went to doctors, clinics, and hospitals when they were ill; children went to schools; and public and private social agencies came to provide a great number of supports beyond the resources of individual families. By the middle of this century there was some rising concern, in fact, that most of the family's basic functions had disappeared. It began to appear at that time that, essentially, the family had only three major jobs to perform: the very early nurture and socialization of the young; the replacement of societal members lost through death; and the provision of an emotional haven from the pressures of the outside world. And by the 1970's, even these functions were said by many no longer to be the exclusive province of the family. Indeed, some said that the family was not only no longer necessary, that it was on its way out, would one day in the perhaps near future be seen only in museum archives and photographs.

This was not a completely shared view among those people linked to institutions outside of the family which were concerned with education, with health, and with social supports. In fact, a good many such people were of the opinion that the family is irreplaceable and strong, that, in fact, its very strengths should be utilized in the service of its members by supporting them within the home. These were the people who were likely to become interested in the possibilities of home-based intervention programs of various sorts, eventually to become involved in bringing services to the home rather than insisting that families leave the home to seek them. These services differed most basically from the earliest "home-based programs" conducted by the families themselves because they were from the outside, were "intervention" programs.

Home-based intervention programs were not completely a product of the last fifteen years, although they may seem so to those of us who pioneered home-based early childhood programs in the mid-sixties. School systems established home tutoring programs for children with special needs long before then. The Visiting Nurse Associations in this country had their beginnings at the end of the nineteenth century. And churches administered to the sick and helpless in their homes in perhaps a less organized and more limited way for hundreds of years before.

However, undeniably, the last decade has seen an unprecedented proliferation of home-based intervention programs in this country. This trend has perhaps been most marked in the field of early childhood education. I was astonished to be informed a few months ago that whereas the home-based program with which I am associated, the Mother-Child Home Program, was one of three in the country when the Verbal Interaction Project created and began its research of the program in 1965, there are now more than 200 home-based early education programs in the United States. From a perusal of the titles of sessions in this Symposium, and the very convening of the Symposium itself, the existence of many other kinds of home-based programs is also obvious. Indeed, I understand that the home-based programs represented here at this gathering can be broadly categorized not only by kind but also as voluntary and non-voluntary. I will be most interested in the reactions of those from the non-voluntary home-based programs to my remarks about ethics in home-based programs, and, in fact, in the reactions of those who represent voluntary programs which are not early childhood education programs. For I will speak from the perspective of my long familiarity with the procedures and values of a home-based early childhood program in which the voluntary nature of participants' enrollment has always been an integral requirement of the program. It is from this experience, and from the observation of other home-based programs with similar aims to my own, that my thoughts about the ethical considerations linked to home-based programs have evolved.

It is possible that the ethical considerations which I shall lay before you are not unique to home-based programs and may be relevant to any social program, whatever the setting. Yet it seems to me that the very advantages that can make a home-based, parent-involving, early education program particularly effective when the child is very young -- ages two to four years, is the ideal period, in my opinion -- are those features that make such a program especially vulnerable to ethical problems. Some of these advantages are: the convenience to the mother, expecially low-income mothers who are often harried and depressed; the familiarity of the home setting for the child; the home visitor's one-to-one relationship with child and parent; and most of all the utilization of the close, enduring parent-child

relationship for the social-emotional and cognitive development of the child. By going into the home and dealing directly with the parent-child relationship, the home visitor comes close to the very heart of what makes humans human. It is a place where one should walk very carefully.

Such a sensitive setting requires more than ordinary vigilance to safeguard the democratic rights of the individuals and families reached by the programs. Among these rights are the right to privacy, the right to retreat to one's home without intrusion by an outsider, and freedom of choice among intervention programs which are not legally compulsory. These are the same rights enjoyed by the patrons of center-based programs for preschoolers. But parents associated with center-based programs can defend themselves better against violations of those rights. If the violations become too much to deal with, they can take their children, leave the center, and go home. Parents in home-based programs don't have exactly this option. They already <u>are</u> at home; in order to separate themselves from a home-based program, they must evict it. This is a hard thing to do. People are more often polite than not. They do not feel it courteous to withdraw hospitality once it has been extended.

I suspect the task is made even harder by the unusually humane and caring qualities of the staff people who work in home-based programs. I know of the latter because for ten years many visitors have come to the Verbal Interaction Project to observe the Mother-Child Home Program, and a fair proportion of them are staff from home-based programs. One of the joys of being at the VIP is the chance to meet and interact with visitors. All of our visitors tend to be rather special human beings by reason of their association and interest in parents and children. But those associated with home-based programs seem to have halos a little brighter, their commitment to their programs and the families a little stronger. They seem to have every one of the traits recommended by one recent author (Morrison, 1978) as desirable in home visitors. They seem to be, to quote his list: "understanding, honest, trusting, compassionate, caring, helpful, sensitive, friendly, supportive, loving, patient, tactful, resilient, kind, empathetic, cheerful, dedicated, enthusiastic, warm, courteous, motivated, persistent." These very traits of the home visitor may paradoxically increase a parent's reluctance to struggle against infringements of his or her own rights.

As for the home visitor and the program which he or she represents, it is difficult for me to believe that they would ever knowingly violate the rights of other persons. Nor do I think that they would intentionally abrogate their responsibilities to the larger social good. Yet it is all too easy to do either or both in a home-based program, simply because staff members may not be aware of the risks. I can think of ten potential ethical pitfalls which could and probably would be avoided in running home-based programs if program staff became more aware of their existence. Many, perhaps all, of them may not be new to you. I offer them as a kind of check list. You may wish to compare it with your own list of ethical considerations necessary to be included in the day-to-day operation of your home-based program. I hope you will add others in our discussion later, or perhaps take issue with those I describe. I will be most interested in your reactions. It will be of importance beyond the immediate issue to hear from those whose programs are compulsory for one reason or another, to hear their judgement as to how many of these ethical considerations can apply to their programs.

ETHICAL CONSIDERATIONS

Ethical Consideration #1

Appropriately, the first ethical consideration arises with the family's response to an invitation to join the program. In their eagerness to help the family the program staff may pressure a parent subtly or overtly. Coerciveness to join a voluntary program is an ethical violation of individual rights. A "voluntary" home-based program can be very persuasively presented to a prospective participant, almost to the extent of arm twisting. It is hard to think of a reason to resist a program promised as coming right into your own living room, if you care about your child -- and practically every parent does. Yet a mother, for her own valid reasons, may not want a program in her house. It should be noted that coerciveness is not only unethical but it is also counter-productive. A coerced mother is also likely to be an inwardly non-cooperative one after the program begins. A mother who is in a home-based program against her real wish may find it harder, not easier, to express her true feelings about participation as the program goes along. But those negative feelings may continue and increase. Mysteriously -- to a visitor so intent on delivering the program that he or she does not recognize the signals -- there are more and more occasions when the mother disappears from home sessions to make pressing telephone calls or to do some cooking in the kitchen. Luckily, there are indeed many indirect ways that a parent can fight back against an invasion of her home even if he or she feels she can't prevent it.

Let me hasten to add that a parent's signaled rejection of a program is not necessarily a function of the program's content or quality. Our own Mother-Child Home Program, for example, is immensely popular with parents, children, and staff not only in our Freeport model program (Levenstein, 1977) but in replications throughout the country -- and in Bermuda. It is a program for promoting mental health and preventing children's later educational problems in low-income families. Its seemingly universal acceptance is understandable, since it consists basically of "Toy Demonstrators" bringing, in two successive school years, weekly gifts of attractive, durable books and toys to toddlers and their mothers, and modeling for the mothers in joint play sessions with the child the concept-enhancing verbal interaction possibilities of these curriculum materials. The Toy Demonstrator must stay within her role and may not teach, preach or counsel. The mother, on her part, is free to heed the demonstration and curriculum or not, as she chooses. She may even set limits on the intensity of the program -- the number of home sessions. What could be more relaxed, even joyous? In fact, when we did an informational film about the program, we called it "Learning in Joy", and no one has ever demurred at the title in the many times it's been shown, borrowed, and rented. Yet a few mothers even in our program have signaled their resistance in the ways I have described. It is a striking indication to me that even the most attractive of home-based programs is not attractive to everyone, and that even home visitors as sensitive and caring as I believe ours to be cannot always inspire mothers to be verbally open about their negative feelings.

Ethical Consideration #2

A second ethical consideration is that involving confidentiality. The violation of confidentiality can include a great range of staff behaviors, from staff disclosure to a colleague, without the mother's permission, that she is in the program at all, to mentioning to a family's neighbor some of the more interesting details of a mother's sex life. Entering into a family's home inevitably means that the family must give up some privacy, that some disclosures must be made intentionally or unintentionally to the person who comes into the home. Preservation of the family's privacy is an ethical responsibility. The degree to which it <u>can</u> be preserved is an ethical problem.

Ethical Consideration #3

Keeping intrusiveness to a minimum poses an ethical problem in regard to the third ethical consideration. Any home-based intervention program entails some intrusiveness. In fact, this applies to all intervention programs, whether home-based or not. Let us note that one of the dictionary definitions of "intervention" is "interference with the acts of others". We cannot avoid this "interference" in carrying out a home-based program, any more that a school, clinic, or social agency can in carrying out its interventions. In order to modify behavior or alleviate distress, one must intervene. The school intervenes by teaching to increase the child's knowledge; the clinic by eliminating his illness; the social agency by providing supports to enable the family or individual to deal with a life problem. Each intervention is "an interference with the lives of others", benign as it is intended to be. One might say that every benevolence carries with it an inevitable price, that resulting from interfering with the lives of others (Gaylin et al 1978). Every responsible intervener is aware of the practical if not the ethical responsibility to keep that price as low as possible: schools teach children to reach out for knowledge themselves; physicians avoid invasive procedures; social agencies refrain from unnecessary intrusions and encourage independence. In a home-based program, ethical considerations weigh very heavily in avoiding intrusiveness, even where coming into the home and taking over seems to be an essential part of the program, as in providing home-maker services in family emergencies. It is ethically necessary to do even this with a minimum of interference, or intrusiveness, into the less tangible aspects of family life, the family's customs, values, way of living. Fortunately, few other home-based programs require such a high degree of interference and can deal more easily with the problem of intrusiveness. But "more easily" doesn't mean easy. At the core of the problem in home-based programs is that the intrusiveness is likely to be subtle and almost always unintended. This, paradoxically, increases the family's vulnerability to it. It is necessary first to identify the intrusive behavior, to become aware of its existence in one's own program before one can eliminate it as far as it is possible to do so. What are some examples of unnecessary, subtle, intrusiveness? They can be as seemingly innocuous as a home visitor making uninvited comments on a family photo ("My, doesn't he look sad!") or walking over to the television set and turning it off. Unfortunately, the illustrations can have as much variety as there are different personalities of home visitors and styles of home life.

Ethical Consideration #4

This brings us to a fourth ethical consideration, that which arises from the family's right to respect for its style of living, its right not to be obliged to give up any part of it which is not absolutely necessary to carry on the home-based program. A French speaking family may understandably prefer to have its life style respected by having assigned to it a home-maker fluent in French and with a comforting knowledge of French cooking. But if none such is available, an English speaking lady whose cooking expertise is limited to hamburgers may have to do. Yet even this mismatch can occur in ways that demonstrate an ethically acceptable attitude, a respect for the family's wishes, beliefs, and ways of doing things although it may be impossible to adapt to them completely.

Ethical Consideration #5

The fifth ethical consideration is not generally thought of as ethical, although it may very well be recognized as a problem. This is the skills-mismatch between the home visitor who delivers the program and the services she must undertake to deliver, A home visitor in a home-based program sometimes must convey dental and nutritional information; give advice about where to get help for medical problems and perhaps transport family members to clinics or other resources; teach a child; teach a mother to teach her child; and counsel the mother on life problems. It is difficult to believe that the expertise for all of this wisdom can be embodied in one person, or that such an unusual person's talents can be purchased at the not conspicuously high going rates for home-visitor salaries. I suspect that it is more often likely that the home-visitor simply makes do in giving these varieties of services by drawing on her own intuitive knowledge and her own life experiences. Rich though these may be, they have not been tempered by the discipline and knowledge base of the long and systematic training it usually takes to be an expert in some of these areas. In my opinion, the size of the disparity between the service the home-visitor supposedly gives, and what she can and indeed actually does give, is a measure of the size of an ethical as well as practical problem. In my opinion, it does become an ethical as much as a program-efficiency problem. I might agree more with a common retort I hear when I raise this problem, "But something is better than nothing!" if everyone felt able to be frank about the skills-mismatch problem. Aren't there inevitable limitations to home visitors giving this variety of services? Is it really possible to eliminate the mismatch through "training workshops" and "ongoing supervision"? If a few weeks of training sessions, and on-the-job supervision are all it takes to qualify people to be teachers and/or counselors, then universities and professional school

preparation for these professions would seem to be unnecessary and should shut up shop. But home-based programs in which the mismatch continues to be demonstrable are surely giving less than first rate services. In that case, doesn't it present an ethical problem to claim one's services to be better than they actually can be in the light of the home-visitor's qualifications?

Ethical Consideration #6

The sixth ethical consideration is closely related, for it refers to "service overload": a program giving more services than the home visitor can reasonably deliver, and more services than the participants really want. Are participants subtly pressured to accept some services from the program because a service the family really wants (such as daycare for a handicapped child) is predicated on their acceptance of other services? Let me hasten to emphasize that service overload by the program should not be confused with aiding a family to obtain from community agencies services requested by the parents. Indeed, the program has a social responsibility to do so, when the parents wish this aid.

I would like to pause, now that I am more than half way through my list of ethical considerations, to read to you some excerpts from a description of an actual home-session with an Appalachian rural family, contained in the recently published book from which I quoted earlier. It serves as a kind of capsule illustration of the need for the ethical considerations I have mentioned thus far.

The home visitor inquires how things have been going with the family during the past week. Past experience has shown the visitor that there are usually problems with the children, for example, the oldest daughter, six years old, has been experiencing seizures. The home visitor has helped the parents go to the Crippled Children's Society to get free medical services in order to have the seizures diagnosed....

In order to reinforce dental and health practices of the family, the home-visitor inquires of the parents. "Are the children taking their vitamins and brushing their teeth everyday?" "Are Mom and Dad doing it too?" The family has put hooks on the wall by the sink which are used to hang up the toothbrushes. Each family member's name is put by a hook along with a record chart for each person to check when they have brushed.

The home visitor also provides vitamins, toothpaste, dental floss, etc., to the family.

Through conversation, the home visitor will inquire about the children's breakfast. "What did you have for breakfast?" "Pancakes?" This can lead to a conversation about how the pancakes tasted, what the children put on them, etc. Sometimes the children may say they didn't have anything to eat. When children respond that they have had nothing to eat, the home visitor will determine if this is a persistent and chronic occurrence. If it is because of a lack of food, money, parent initiative, family problems, etc., this will more than likely be an area in which the home visitor will spend time developing activities and reinforcing concepts with the parents concerning the importance of good nutrition. In addition, the family will be

helped to deal with these problems. At Christmas time, the home visitor may take baskets of groceries and from time to time, will get an emergency food order from the Community Action Agency of Department of Welfare so that the family may have food. It could also be the case that this family isn't aware of the federal food stamp program. If so, this will also be an area in which the home visitor will provide help. (The amount of money a family spends for food stamps, if any, depends on family income, bills, and other family responsibilities.)

The family is next asked to get their monthly plan so it can be reviewed by the family and the home visitor. This monthly plan is discussed with the parent each month and is developed with their help. Parents are always asked if they have any ideas for conducting activities, solving problems, etc. Quite often the parents do suggest different ideas, for example, using coffee cans and buttons for conducting a classification activity.....

The next activity which the home visitor helps the family with is a craft activity of stuffing a necktie. Everyone is shown how to make a "snake" stuffed animal toy. There is a discussion about what the animal is, its color, shape, length, etc..... For the younger children, as a follow-up activity, a piece of cardboard can be punched with holes to form shapes, initials of names, designs, etc. These pieces of cardboard can then be "sewn" with string. The home visitor brings the cardboard and the parent provides the needle, string, etc. This is an important process since the home visitor doesn't want to do everything for the family.....

Prior to the conclusion of the visit, the home visitor shows the mother activities she wants her to do with the children the coming week. In this particular case, they are a review of the concepts of color, shape, size, classification, and weight. These concepts had been introduced before. The home visitor also reminds parents of the forthcoming parent meeting. Arrangements are made to have a neighbor provide the mother with a ride. The father has volunteered to baby-sit so the mother can attend the meeting.... (Morrison, 1978).

The decency and real concern of this home visitor are very apparent. Less evident are the reactions of the various family members to all of this kindness. Are they really as receptive as they appear in the report? Or are there some unspoken resistances which will find expression in sabotage of what this good person is trying to teach? Regardless of family attitudes to the program, several of the six ethical considerations I have suggested thus far should probably be applied to this home session. I will leave it to you to decide which!

Ethical Consideration #7, 8, 9, 10

The last four ethical considerations which I would like to lay before you pertain to what might be called the ethics of program evaluation. Every program is given some kind of evaluation. It might not be called an "evaluation", but every administrator or program staff person who has judged the program worthy of being delivered has thereby conducted an informal evaluation and has judged that the program is effective on some

level. Certainly, the recipients of the program have been given to understand that somehow this home-based program is going to do them some good. It seems to me that the people responsible for the program have a certain social responsibility to show that resources like money and staff time and work are indeed going to do the recipients -- or somebody -- some good. Therefore the last four ethical considerations to be offered here refer not only to the rights of program recipients but to those of society at large, to some kind of systematic program evaluation. We might call them "socio-ethical" considerations.

The first socio-ethical consideration in this cluster of four refers to program goals. The initial step in gathering facts relevant to the social accountability of a home-based program would seem reasonably to be a concrete definition of the program's objectives, a practical translation of the program's broad abstract goals into something tangible. In the home visit description I just read, what was very likely stated as a broad goal of "Improve family dental health" seemed to have been translated into the question, to the parents, "Are the children....brushing their teeth every day?" Operationalizing the goal in this way is an aid to reflection about the most fundamental aspect of any program, its purpose. If the purpose of promoting dental health comes down to the objective of having a maximum number of parents say "yes" to this question, a program reviewer has the option of either agreeing that this is a sensible rendition of the goal, or not. But at least there is up-front knowledge of what he or she is accepting or rejecting. A common problem for all programs, not just home-based ones, is that excellent goals are usually too broad for really understanding what the program is aiming to do.

Specifying <u>goals</u> can sometimes require such a heavy investment of thought and time that there is a tendency to confuse program goals with program <u>methods</u>. This seems to me rather natural, when a goal is inextricably linked to a method, as it seems to be in the "Are the children brushing their teeth?" example above. The question has the purpose not only of counting tooth brushers, but is a method of reminding them that those teeth should be brushed. It is a way, a program method, for achieving the goal of dental health. It should be named as both a goal and a method. Its relevance to the second socio-ethical consideration is that very point -- the item should be named, and it should be placed in the context of defining the total program method. Otherwise it is difficult indeed to say what the program <u>does</u> to accomplish its <u>goals</u>. Vagueness of program method is a problem to which home-based programs seems especially prone. When asked about our method, we are all tempted to say, "We work with the family!" and let it go at that. Alas, it's not enough.

It's especially not enough when taken in relation to the last two socio-ethical considerations. One involves the hazards of making claims for the amount and quality of program delivery without close monitoring of the program which is actually being delivered. And the last socio-ethical consideration relates to the propriety of making claims for the program's effectiveness without adequate evaluative data. Both considerations require a prior clear definition of just what the program is and does. It is impossible to claim that the program is well delivered if one cannot say what the program was ideally supposed to be. Similarly, there is no point in claiming a program's effectiveness if one cannot say just what the method was that was effective. But along with a clear definition of the program's method as specifically defined, on paper or otherwise, there is s socio-ethical responsibility to investigate and demonstrate in some way that the program is the one being delivered to the home. This is truly hard to do in the delivery of home-based programs. If the story of what happens in a family's home depends completely on the home visitor's self-report, which may be unconsciously biased, no matter how honest the reporter, then the program is not really being monitored. The claim cannot be made with any assurance that the program as planned is the one being delivered.

Claims of the program's effectiveness cannot be made without evaluative data systematically collected in a way which follows generally accepted evaluation standards. This last socio-ethical consideration is a difficult one to deal with if program personnel have no evaluation expertise and have no idea whom to turn to for such help. However, a giant step in the direction of a socio-ethical attitude in regard to program claims of effectiveness is to understand that enthusiasm is no substitute for sound evaluative data. A large part of that understanding is the awareness for example, that the mere gathering of numerical information is not enough. The number of times the parents said "yes" to the question "Are the children brushing their teeth"? may seem to have meaning as a program result, but actually has none, without many other factors being taken into account. It is also helpful to be aware that a listing of program goals is not a listing of program effects. What we wish and hope our programs will accomplish is still only what we aim for, not necessarily what actually results from the program. It is ethically important that we understand the distinction between the dream and the reality of a program. The next step is to find help with at least modest program evaluation. My guess is that advice about this is within the reach of the majority of people responsible for program delivery. Excellent articles and books are available. Every state has at least one university, with faculty members knowledgeable about research. My guess also is that almost any program person can

collect some important data about his or her program operation and its results, which may be limited in scope but which can be helpful in measuring outcomes. But if a systematic evaluation is truly impossible to come by, then it seems to me that a program has no ethical choice but to be extremely cautious in its claims of effectiveness.

FINAL REFLECTIONS

I have presented ten ethical considerations to be taken into account by home-based programs. Six directly involve program participants and encompass the problems of coerciveness and intrusiveness, especially the subtle variety; confidentiality; respect for family life styles; mismatch of home visitor skills to home visitor task; and service overload. The other four have to do with the socio-ethics of program evaluation: the need for definitions of goals and method; of monitoring the quality of delivering the method; and of systematic program evaluation to provide the evidence for the presence or absence of the program's success. I can't think of a kind of home-based program to which these considerations would not apply, in greater or lesser degree, with one possible exception. The exception is the non-voluntary home based program. I am frankly puzzled as to how a program which by definition is invasive, because it is non-voluntary, can safeguard the civil liberties of a family, its rights to privacy, to being at home without intrusion, and to freedom of choice.

That it is possible for voluntary home-based programs to heed these ethical considerations without sacrificing program standards seems demonstrated by the fact that at least one home-based program has been able to do so. The Mother-Child Home Program has built in what appear to be real safeguards against the problems raised by these considerations and has maintained them year after year in the 12 years of its existence in its present form. Moreover, 29 replications of the program throughout the country were able to follow the same criteria and practices for two years and thus achieved certification, the official approval of the Verbal Interaction Project, which is the standard-setting research parent of the program. It may be of special interest to this audience, which may contain some social workers, that one of the VIP's two sponsors is the Family Service Association of Nassau County, a social service agency, which in turn has had a close tie to the Family Service Association of America. Humanistic, social work values have played a major role in our maintenance of ethical standards, just as the scholarly, scientific values of the academic community have also permeated the Verbal Interaction Project, particularly through our other affiliation, the State University of New York at Stony Brook. Both have undoubtedly influenced

my choice of ethical considerations to put before you in this presentation. The ten I have chosen are the ones that seem to me the ones most urgently pressing in the delivery of home-based programs.

But perhaps there are others of far more significance which have not occurred to me but which are of paramount importance in your own situations. Or perhaps the ones I have named seem irrelevant to your situation. I am most interested to hear your thoughts about this and look forward to a lively discussion with you.

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